

Slow Progress in Cancer Care Disparities: HIPAA, PPACA, and CHEWBACCA. . . But We're Still not There!

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Despite very high health care expenditures, the United States does not offer a uniform standard of medical care to its population, and egregious deficits in cancer care continue to exist in various segments of our community, leading to significant disparities in outcome [1–5]. This lack of equity in the health care system can collectively be termed “disparity of care” [1, 4, 5], and this may affect ethnic and racial minorities, the elderly, the indigent, and some geographically isolated populations. Although there are many relevant definitions, the U.S. Department of Health and Human Services defines health disparities as “differences in the incidence, prevalence, mortality and burden of diseases and other adverse health conditions that exist among specific population groups”. The importance of these issues in health care systems was summarized comprehensively in the recent report of the President’s Cancer Panel [3] and in a policy statement from the American Society of Clinical Oncology [1], each with a series of substantial structural, functional, and strategic recommendations.

The Oncologist has decided to focus further attention on this crucial topic in the hope of reminding our medical community of the problem, addressing the extant problems, and contributing potential solutions. In this series, experts in the field have covered the key issues that relate to the problem, its underlying causes, and potential solutions.

Several factors (Table 1) appear to contribute to these

differences in cancer outcomes, and these must become part of our medical consciousness as deficits that require urgent attention and/or resolution.

What is very clear is that this problem is not unique to the United States. As outlined in this issue by Olver et al. [6], significant deficits in cancer outcomes are experienced by minority populations in Australia and New Zealand, predicated on the same predictable factors—poverty, social and geographical isolation, education, cultural prejudices, and access to care. Similarly, in the United Kingdom, ethnic minorities have important deficits in knowledge about screening programs [7], and it is clear that these differences extend into the domains of prevention and treatment. This is particularly important when one recognizes that Australia, New Zealand, and the United Kingdom have significant elements of nationalization in their health care systems, indicating that a single government payer offers no panacea!

As noted by Moy and Chabner [8], the recent PPACA legislation, enacted by the United States government, addresses several key issues that will improve access to care in the United States, but also suffers from some major potential deficits in framing, funding and the potential for execution, so that the problem appears still to be unresolved. They point to the well-recognized importance of patient navigation, and the need for its federal support, but draw an important distinction between “authorization” and availability

Table 1. Factors associated with disparities of cancer care
SOCIO-ECONOMIC:
<ul style="list-style-type: none"> • Poverty • Educational, linguistic and literacy barriers
ACCESS:
<ul style="list-style-type: none"> • lack of health insurance • lack of medical “home” • lack of access to care, including: <ul style="list-style-type: none"> ○ clinical research ○ prevention ○ screening ○ diagnosis ○ treatment ○ education
CULTURAL:
<ul style="list-style-type: none"> • minority community suspicion of health care systems & providers • stigmas associated with cancer and death • low community expectations of outcomes of cancer treatment
MEDICAL ISSUES:
<ul style="list-style-type: none"> • co-morbidities in underserved subjects • delays in diagnosis <ul style="list-style-type: none"> ○ under-utilization of screening ○ lack of knowledge of appropriate diet, obesity ○ lack of knowledge of genetic factors ○ lack of knowledge of environmental and behavioral causes
HEALTH PROVIDER/SYSTEM FACTORS:
<ul style="list-style-type: none"> • overload • system funding • lack of medical “home” for underserved patients • errors of clinical practice • language and cultural barriers • social stereotyping • paucity of available research and data on disparities of care and their causes

of funding in the legislation. At a broader level, health care funding is in crisis, and it is likely that there will be less funding available to cover these issues in the future.

Other key distractors can complicate discussions focused on solutions for the disparities of medical care. For example, considerable effort has been expended on definition of terms such as race and ethnicity, in some cases holding up attempts at improving obvious deficits in care in favor of academic purity. Self-identified race or ethnicity (SIRE) is widely used as an index. However, this is subject

to the vagaries of family legend, and it has been suggested that this parameter is more useful as a socio-cultural index rather than having a role in specific treatment or research planning [9], and that specific genetic studies are more informative in this context. The alternative view is that, for whatever reason, there are genetic variations that are associated with SIRE, and that this index should not be dismissed [10]. Rebbeck et al. propose that, with the paucity of extant information, SIRE and genetic information should be integrated and applied to disparities research to the extent possible [11], a view that seems pragmatic and sensible, and superior to the concept of delaying further studies pending a perfect definition. The history of intervention against disparities in care has intermittently been characterized by the philosophical struggle between pragmatists and purists, with the implementation of any strategy often being aborted for unconvincing reasons—so-called “analysis paralysis.”

The situation is further complicated by the fact that the impact of the factors enumerated above is not symmetrically seen across the health care system, nor is there consistency in the various under-served populations. In our series of articles, Yung et al. [12] have illustrated the different impacts of similar adverse socio-economic factors on two diseases, Hodgkin’s lymphoma and acute myeloid leukemia, when reviewing large databases. Enrollment in Medicaid did not compromise outcomes in acute myeloid leukemia, although poverty and race were adverse contributing factors. Medicaid patients with Hodgkin’s disease were predominantly treated as outpatients, and the lack of socio-economic support may have contributed to the worse reported outcomes. In the instance of acute myeloid leukemia, the heavy emphasis on inpatient care may have contributed additional social support, which may have overcome some of the baseline socio-economic impediments to success.

By contrast, our group, in a study of linked records from the Ohio Cancer Incidence Surveillance system, Ohio Medicaid enrollment files, data from Ohio death certificates and from the U.S. Census, have shown that enrollment in Medicaid after a diagnosis of cancer is universally associated with a worse set of statistical outcomes than found among patients who were already enrolled in Medicaid before their cancer diagnosis [13]. In this study, the outcomes in both situations are significantly worse for Medicaid patients as compared to those not receiving Medicaid at any time. We reviewed eight different cancers, including Hodgkin’s lymphoma and acute lymphoblastic leukemia. This simply illustrates the complexity of the problems, and the importance of research and documentation of a broad range of variables that may impact the algorithm.

Finally, although much of the current emphasis on disparities is focused on immigrant populations and on people of color, the reality is that substantial problems also exist for some majority (Caucasian) populations, as indicated by Paskett et al. [14] in their review of the impoverished communities of Appalachia. As in the studies enumerated above, common variables of poverty, level of education, social isolation, co-morbid conditions, lack of insurance, and lack of a medical home present themselves as unifying problems for each of these underserved groups.

When addressing the challenges and solutions to the problems of disparate cancer care, one can compartmentalize into key areas: (a) design and implementation of more effective cancer prevention and control strategies; (b) improvement in promotion of early diagnosis; (c) enhancement of access to treatment and to cancer clinical trials; (d) refinement of strategies for treatment in specific underserved populations; and (e) more precision in the measurement of health outcomes that are important to these communities; (f) critical need for more research in the entire domain of disparities of care. These are addressed, on an international basis, in this series of important papers.

There has been slow progress in some domains, reflected in recent surveys of national outcomes, where it is clear that minority and under-served populations still have worse incidence and survival [1–5], irrespective of the presence or absence of nationalized medical systems. Despite

the increasing recognition of the disparities in cancer care, it does not appear that the gap in survival is narrowing sufficiently quickly. That said, the work in Appalachia [14] indicates that real progress can be made in a finite period, and as discussed by Brawley [15], patient advocacy organizations are also becoming more focused and more organized on these issues, bringing additional pressures to bear on government while incorporating involvement of relevant under-served community leaders as a keystone to their progress.

The President's Cancer Panel, in its recent report, has made a series of iconoclastic, important recommendations, focusing on solutions, and holding specific groups accountable for future progress. They advocate for dramatic improvements in data acquisition, holding the President and his staff members responsible for initiating the process. They encourage government agencies at local, state and federal levels to begin to cooperate, and to improve the level of cooperation in the area of disparities of care (amazing that governments need to be educated in this fashion!). They hold *all* stakeholders responsible for improving the level of research and provision of health care, in parallel with provision of social support. They have correctly identified that this is a national community responsibility. The challenge has been set—we need to begin to meet it TODAY.

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